The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes

Working Papers from the AKTIVE project 2011-2014

AKTIVE Working Paper 5

Lifestyles in Later Life: identity, choice and stigma

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Advancing Knowledge of Telecare for Independence and Vitality in later lifE

Technology Strategy Board
Driving Innovation

1 Introduction

This paper explores the identities and lifestyle choices of older people participating in the AKTIVE study and considers how telecare can support the maintenance of independence and preferred identities. The paper focuses on strategies and situations which enable older people to retain important elements of their identity, including their attachment to home and good relations within families. It also examines the circumstances in which telecare can be a source of stigma for older people, compromising self-perceptions and viewed as a sign of dependency.

In exploring these issues, the paper complements and draws upon analyses presented in other AKTIVE working papers, which focus on: the study sample and the telecare in place (Yeandle, 2014a, Paper 1); older people's caring networks and how these are affected by telecare (Yeandle, 2014b, Paper 2); how telecare shapes and affects older people's social relations (Koivunen, 2014, Paper 3); its relevance in older people's responses to their bodily frailties (Fry, 2014, Paper 4); and its role in how older people manage perceived risks to their independence, safety or wellbeing (Hamblin, 2014, Paper 6 and Buckle, 2014, Paper 7, both forthcoming, May 2014).

The paper draws on research evidence about who the older people in the AKTIVE study felt they 'really are'. Using three key concepts, 'identity', 'choice' and 'stigma', it explores the subjective realities older people shared in talk and interactions during research visits over six to nine months in 2012-13.

Identities have been conceptualised in other research as either fixed or transient; some theorists claim they are continuously adapted in line with personal choice and changing circumstances (Bradley, 1996). Furthermore, different factors, '[*gender*] *… race, class, age, family role and workplace role are all potential identifications that may or may not structure consciousness at different times and in different ways'* (Giles, 1995: 12). Goffman (1959) developed the concept of 'dramaturgy' to describe the socially constructed nature of identity, characterising the social world as like a play where people learn how to perform assigned roles through their interactions with others. This paper is concerned with identities in the specific contexts of later life and of private homes with telecare support in place.

In section 2, the paper explores past and present sources of participants' identities, as articulated by them or those close to them. Ageing, and the changes associated with it (retirement, new health conditions, loss and bereavement), have been identified as potential catalysts for an 'identity crisis' or at least a change of self-perception, through which the person adapts to a new identity as 'an older person'. This role as an 'older person' can create 'stigma', classically defined in social science as 'spoiled identity' (Goffman, 1963), and the paper also examines the processes whereby some AKTIVE research participants' identities were, in this sense, spoiled or damaged, and the 'identity-management strategies' used by older people to maintain or protect cherished elements of their identities and the role of telecare in these choices, behaviours and strategies. These are conceptualised as a form of 'resilience', the dynamic process whereby people adapt to adverse situations, and in relation to stigma, how they manage spoiled identities.

The paper draws on data collected using the 'Everyday Life Analysis' (ELA) methodology outlined elsewhere (Yeandle et al., 2014). This method combined a variety of elements to gain a rich, contextualised account of older peoples' lives and to assess the role of telecare within them, not only from their own perspectives, but

also from the viewpoint of those involved in caring for or supporting them (whether as paid home care workers or as family or unpaid carers). This holistic, person-centred method, which allowed the researchers to keep the older person at the centre of their own stories, was extremely fruitful in producing data on issues related to identity and stigma.

Within the sample, almost two-thirds (39) of participants were female and over half (41) were living alone (32 in widowhood); 17 participants were married, eight were divorced and two were single. As explored in Paper 4, (Fry, 2014), participants' health varied from those who were very frail and unable to attend to their own daily needs[1] to those who had few physical impairments but suffered from memory problems (Table 5.1). Over time, the health status of some participants changed, some becoming more physically frail or cognitively impaired while a few saw improvements in their conditions. At the start of the fieldwork, telecare support for about half of participants (32) was only a pendant alarm. Some (22) received upgraded telecare equipment as part of their involvement in the study (including 15 who previously had only a pendant alarm). However twenty-one research participants had telecare 'packages', including sensors to detect smoke, carbon monoxide, temperature extremes or flood / water spillage, and four had a GPS tracker system.[2]

When asked about the events preceding the acquisition of telecare, many research participants were unclear about whose idea installing telecare had been, in part due to the fact that, for many, it was installed at a time of distress and upheaval. Some knew it had been suggested by family members, others involved in their care or health and social care professionals, but many were unsure exactly who had instigated the installation. As also discussed in Koivunen (2014, Paper 3), three main sets of circumstances tended to precede the installation of telecare: changes in participants' health (often involving hospitalisation, a fall or progress in their dementia); changes in their living arrangements (including bereavement which often left them as the sole occupier of their home); and (seen less frequently) 'inheriting' telecare from a previous occupant (sometimes a spouse who had died) or having telecare 'as standard' on moving to supported housing.[3] Very few participants had actively sought out telecare themselves. This meant there was a limited sense of 'ownership' of the telecare, even among those in Oxfordshire who paid for the service.

There was also confusion among many in the sample about maintenance of the equipment and how it worked, and for some a lack of awareness of who to contact about these issues. Previous studies have shown that timely introduction of telecare with adequate information can significantly improve acceptance of the technology (Bayer et al., 2007; Magnusson et al., 2004; McCreadie et al., 2006). Evidence from the AKTIVE study which sheds further light on this, and the degree to which using or accepting telecare can be viewed as part of an 'identity-management strategy', are also explored in this section, after consideration of issues of identity and stigma.

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[1] These daily needs have been conceptualised in the gerontology literature as 'activities of daily living' (ADLs) and 'instrumental activities of daily living' (IADLs) (Bookman et al, 2007).
[2] Two further participants had a fall detector and a gate exit sensor only.
[3] In Oxfordshire, telecare recent developments affecting sheltered housing included replacing on-site wardens with telecare in some instances.

2 Identity, stigma and resilience

Older people's identities

Four main aspects of their identities were highlighted by research participants: identity as a family member; as a worker, professional or skilled person; as an active, independent or capable person; and as a homemaker, homeowner or local community member.

In the study, older people frequently identified themselves in relational terms, as wives or husbands, parents, or as someone's son, daughter, brother or sister. Those who had cared for family members in the past often highlighted this as central to their identity; some still provided support to grandchildren or, in a few cases, to an adult child with a learning disability.[4] The research visits and interviews prompted some participants to reflect on whether they had been 'good' at these roles, which for some had been an important source of self-worth; many spoke of these roles in the past tense, however; their family identity had already shifted (through processes explored in the following section).

Employment was an important topic for many within the sample, as former work roles had provided an important source of identity, and work was acknowledged as a context in which their skills had been valued and they had interacted with different people. Some spoke with pride of accomplishments in their working lives, particularly those who felt their 'start in life' had been compromised by poverty, limited formal education or the outbreak of World War II. For both men and women, the war had often provided their first experience of employment, either in the armed forces or in workplaces supporting the war effort, such as army laundries or munitions factories, and some vividly recalled these experiences from 70 years ago.

During the research visits, most participants were keen to discuss how active and independent they were or had been in their younger years. Independence was a prized attribute, and many spoke of being able to 'look after themselves'; emphasising what they were still able to do, as well as what they now found difficult. Some recounted in great detail activities they used to undertake, especially before the advent of labour-saving devices, and some still felt they were very capable, often adding the caveat, 'for my age'. Some research participants spoke of their gendered identities as active men or women, reflecting on past efforts they had made with their appearance, how physically fit they were, and the gendered activities they had engaged in.

Most research participants expressed some aspects of their identity in relation to place, especially their homes and neighbourhoods. Many had lived in their present homes for over 30 years, some for as many as 50 years. Their homes were often a great source of pride; the place which some had saved and worked hard to buy; where many had brought up their children; and which, for some, had been a means of overcoming stigmatised circumstances in childhood or early adult life.[5]

Neighbourhoods were also places where they had participated in local activities and supported others; where they had felt safe and valued; and where they had experienced a sense of belonging. These homes

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[4] For a fuller exploration of caring dynamics within the sample, see Yeandle, 2014, Paper 2 in this collection.

[5] For some research participants who described themselves as 'working class', their clean, well-kept homes were an important part of their identity; one who had migrated to England at a time when discrimination was prevalent emphasised that keeping her home immaculate had been a means of combating the racism she encountered.

and neighbourhoods were the sites of memories, and had been spaces where the person had agency and made changes (for example, decorating, taking part in community events or activities, or campaigning). Due to their present frailty and ill-health, some participants felt these environments were now increasingly controlling them or constraining their activities and decisions; some were now afraid or unable to go out alone or to access certain areas of their home.

Identity change in later life

Indicating that they felt their identities had changed, or were changing, many older people spoke about their identities in the past tense; some experienced the processes involved as 'stigma', or spoiled identities.

Three processes described by participants indicated that relational identities were at risk or had been damaged: bereavement, changing roles and estrangement from family members. Bereavement, particularly after the loss of a spouse[6], altered some participants' identities, and contributed to feelings of isolation as social worlds contracted (see also Koivunen, 2014, Paper 3). On a practical level, bereavement often led to changes in activities; tasks that had been divided between a couple were now the sole responsibility of the surviving partner, or, if they could not be managed, had to be shared with others: carers, friends or sometimes care workers. For widowed participants whose relationships had involved a gendered division of labour, this often meant acquiring new skills. One explained:

> *It's very difficult* [...] *when you've got to start looking after yourself and doing things for yourself. I've never had to do it; my wife was always here, and if I wanted anything, my wife was here.* [...] *When I got really bad she would look after me. But once she'd gone, I was completely lost. I didn't know where to start.*
>
> Mr Shaw, 73, living alone, falls, Oxfordshire[7]

Changes in family roles as capabilities declined also caused some participants distress. Many had given care or support to family members in the past, but now found roles reversed due to their own care needs. Mrs Hall remarked: *'I was quite active; going out here and there and everywhere, take the children out. Now it's the children who come and take mother out'* (77, living alone, Oxfordshire). These research participants felt 'lost' within their social relationships as they struggled to shift their identity from 'carer' to 'cared for'; they frequently expressed a desire not to be burdensome to their families and friends, often commenting that they already had many demands on their time. Some of those who now received help or support from family members with daily living activities felt stigmatised and self-conscious about this:

> *Sometimes I get a bit embarrassed about having a meal out, in case I don't quite judge it, see it, like.* [...] *if my hand's bad, and, [carer's name], she'll cut something up for me, you know what I mean, to make sure* [...] *She turns around so nobody can see her doing it.*
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> Mr Whittaker, 77, living alone, falls, Leeds

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[6] While some participants expressed idealised views of marriage in 'the old days' or described later life as harmonious, there were also examples of widowed and divorced participants who felt they were in a better situation now they were living alone.

[7] All research participants' names have been changed. Further details of individual research participants are given in an appendix to the AKTIVE Working Papers.

Estrangement featured in those cases where there had been disagreements or rifts within families. In a few cases, the research participants were no longer on speaking terms with some of their children, grandchildren or siblings. This was a cause of distress for some as they felt they were 'missing out' on family occasions and interactions (particularly with grandchildren), while others were more accepting of this state of affairs.[8] As already outlined, those for whom paid employment had once been important took great pride in describing their work. After retirement, many experienced a sense of loss, particularly those who felt they had left work 'before their time' due to ill-health. Some had worked as care professionals or within the health and social care sector; for them, accepting care themselves could be particularly hard to bear.

The most frequently cited sources of stigma were the challenges posed by ageing and ill-health, which often damaged a past identity as an active and independent person. Becoming physically less able constrained the activities participants could manage, and many spoke of feeling 'useless' or 'hopeless'. Physical frailty was for some participants at odds with their mental abilities, and some of these participants felt 'trapped' inside bodies that were 'too old' for them:

> *I never thought I'd be like this, but* [my daughter] *said, 'Well, mum, you are 90, really'. But I don't feel it, you see? That's the trouble; I don't feel it, and I'll talk to people just as if I'm the same as them, but I'm not, you see?*
>
> Mrs Richards, 93, living alone, falls, Oxfordshire

Where a sudden illness or injury had plunged the person into 'old age' and enforced passivity, adjusting to life with a newly-acquired physical disability could be very hard. Ill-health, and in some cases operations, had led to physical changes, including weight loss, scarring, amputations and lifestyle changes, which affected how they felt about themselves and undermined their sense of being dignified or 'proper' men and women. These bodily changes meant traditionally gendered activities which, as they described it, had previously marked them as men (being active and physically strong) and women (taking care of their appearance and domestic tasks) were now more difficult. Their reduced ability to conduct seemingly mundane actions, such as chores, caused them anxiety and embarrassment about what some felt were their now ill-kept or untidy homes and gardens, and also served to remind them of what they could no longer do unaided.

Issues in adjusting to ill-health were pertinent for some of those in the early stages of dementia or experiencing memory problems, who were sometimes acutely aware that they were starting to forget things. Some had withdrawn from social situations out of fear of causing embarrassment to themselves or the people they would socialise with. Although difficulty remembering things, and the anxiety this produced, was an issue for some participants, some people with a diagnosis of dementia had not themselves been informed of their condition, or felt they had 'got better'.

Driving, which had often been stopped due to increased frailty, was sorely missed by several participants. Though some accepted this as a rational step, particularly the few who had been involved in accidents, without a car they felt increasingly isolated and dependent on others, especially if they lived in remote locations. Mr Fuhrman explained:

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[8] A deciding factor was the duration of the estrangement (with participants having adjusted to long-running conflicts) or whether the research participant had been the person to take the decision not to engage with their family members.

> *I feel as though I've lost my legs; I was at least able to get around, but now I have to depend on other people in the village to take me anywhere. I miss my car very much [...] It's like my independence, just pop in the car and go anywhere, wherever I want, when I wanted to.*
>
> Mr Fuhrman, 93, living alone, falls and memory problems, Oxfordshire

The stigmatising processes which some participants identified were reinforced for some when others defined them as 'old', vulnerable or frail, or felt there were activities or 'risks' they should no longer undertake (issues considered in more detail in Hamblin, 2014, Paper 6 and Buckle, 2014, Paper 7). Some came to realise they were now seen as old through dialogue with family members or health and social care professionals; for others, these interactions reminded them of difficulties they were experiencing which they had perhaps hoped were not immediately obvious.

Within the shift toward acquiring a new identity as 'old', mobility aids, home adaptations and the telecare in place were often experienced as 'old age signifiers', which for some threatened their self-esteem and sense of dignity. Family carers who were interviewed often explained that the person for whom they cared was reluctant to use certain aids, as these conflicted with their idealised view of themselves as a capable person who was 'not old yet'. Although some aids were accepted, especially where the person felt involved in their choice or introduction, these were generally viewed as the 'least worst' option. Mrs White, for example, had both a walker and a mobility scooter, but would not use the latter as she felt it made her look *'about 900 years old, with no dignity or elegance'* (76, living alone, Oxfordshire). Some participants also felt telecare devices worn on the body were unsightly or not in keeping with how they wished to present themselves.[9] Within the AKTIVE sample, pendant alarms were often 'left within reach' for example on walking frames or tables, or worn but concealed under clothing, a practice which made them potentially difficult to activate in an emergency.

The importance of home and community to research participants' sense of self and identity has already been outlined. Their statuses as homeowners, homemakers or members of the local community were also often challenged by bodily changes and frailty. Areas of their homes, gardens and local areas were becoming inaccessible or 'out of bounds', either because their bodies no longer allowed them to negotiate them or because others who cared for them felt it was unsafe for them to do so. This created a dilemma for many, who wanted to remain in their homes, yet were aware that to do so some changes, not always seen positively, would be necessary. Spaces such as 'front rooms', once used for socialising, became bedrooms, bathrooms and toilets as beds, commodes and other aids were installed after previous sleeping and toileting arrangements became impossible when stairs could no longer be negotiated.

This shift in the purpose of living rooms, from social to private spaces, created embarrassment for those affected and made them feel self-conscious. Some participants viewed items such as hoists and hospital beds, in some cases installed to promote safety by their carers or at the insistence of health and social care staff, or the removal of familiar objects deemed hazardous, such as rugs and coffee tables, as an imposition.

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[9] López and Domenech (2008) also found some people felt telecare was a signifier of a 'fragile body' and as a consequence rejected it, in order to retain autonomy over what they felt was still a 'vigorous body'.

A few felt they had not fully consented to these changes to their homes. As one noted, '*they say, well, it's your house - but it isn't any more really*' (Mr Crosby, 79, living with his wife, falls, Leeds).[10]

It was often within these contexts, with painful changes ongoing, that telecare was introduced. As a consequence, many participants were unsure about who instigated the installation of telecare, how the devices worked, what would happen when they were activated and who to contact in the event of a fault. This lack of clarity, it could be argued, prevented the research participants from forming a sense of 'ownership' of the telecare and, in turn, could prevent them from using it in an empowering way. One participant with dementia found the presence of the equipment at times disturbing, as she could not remember when or how it came to be in her home. Those who received upgraded equipment as part of the project were asked what they felt about it; most felt the newer 'Lifeline' unit connected to the telephone point looked better than the previous model, as it was smaller and more discreet.

Identities were challenged not only by reduced control over *what* was happening within their homes, but also by *who* was entering them to provide support. Many explained that, at least initially, they had resisted having home care or other paid support in the home as they felt, or wished to be seen as, independent and capable. For some, concerns were heightened by their experience of home care agencies and care workers. Some felt anxious about security issues, such as care workers' use of key safes to enter their properties, or were worried by long and inconsistent gaps between home care visits (which also troubled their carers). Some women in the study had found it disturbing to be attended by male care workers for personal care, especially if they had requested a female worker. Some felt receiving any type of formal support marked them as no longer independent.[11]

Many participants felt their 'sovereignty' over their own home was undermined by the presence within it of unwanted people (care workers) or devices (such as hoists or hospital beds); however for most the ultimate detachment from a deeply felt sense of place was moving home. A few (four) felt, or during their involvement in the study were encouraged by family members, carers or professionals to feel, that they could no longer safely negotiate their own homes and should move to accommodation more appropriate to their capabilities, such as sheltered accommodation, smaller houses or bungalows, residential care, or closer to family members. While some felt these moves were sensible, they nonetheless experienced them as a 'wrench'.

Social embarrassment compromised participation in the wider community for those who did not wish to be seen as less competent, and particularly for those with incontinence or memory problems, which were a particular source of shame and stigma. Many also expressed concerns about changes in their local neighbourhood: people they had known had moved away or died; new community members seemed less friendly and helpful; crime, or fear of crime, was a problem for some. These issues made some research participants feel uncomfortable about socialising, and reduced their engagement with communities which had once been a familiar and important part of their identity.

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[10] These findings echo Heywood's (2004) study of housing adaptations, which found that the meanings people attached to their home, and whether they saw changes as a form of intrusion, affected their feelings towards not only the alterations but their wellbeing more broadly.

[11] Bowes and McColgan (2013: 44) found people '*resisted receiving services and fought against "giving in" to their impairments; for many of them, becoming a service user was in some senses an admission of failure*'.

Identity-management strategies and the impact of telecare

Many older people in the study managed challenges to the valued identities outlined earlier through the exercise of choice and the use of 'identity-management strategies'.[12] The telecare provided to support them at home played a role for some in retaining a sense of self and identity and this is addressed in this section.

Participants adopted particular strategies in response to three processes which threatened their identities as family members: estrangement, bereavement and changing roles. In cases of estrangement, some participants re-established contact and became reconciled with family members. Mr Swallow, who was 74 and suffered from both falls and memory problems, lived with his wife in Oxfordshire. He had not spoken to his daughter for many years when Mrs Swallow, a keen user of ICT, made contact with her via 'Facebook' on her tablet device. After a period of re-adjustment, he started to interact regularly with his daughter via Skype. He was enthusiastic about this, as it enabled him to see his grandchildren who lived many miles away.

Following bereavement, some research participants opted to keep their homes 'as they had been' while their spouse was alive, claiming they found comfort in items that had been important to them and that sorting through and disposing of their belongings would be painful.[13]

Where familial relationships changed, research participants adopted various strategies to prevent damage to their identities. Some accepted these changes as part of the life course; for them, the shift in the direction of care and support between young and old felt natural, and this helped them accept changes in their lives. Miss Chester remarked:

> *I've done my share of looking after... I've got them* [her family] *to help me. What goes around comes around, doesn't it?* [...] *We've always been a loving family, you know, one for each and each for one.*
>
> Miss Chester, 89, living alone, falls, Leeds

Others resisted change, doing all they could to preserve existing relationships. Addressing a common concern 'not to be a burden', some concealed developments or engaged in a degree of deception to hide problems from those who cared for them. Mr Maveritt (71, living alone, Leeds) spoke at length about his loneliness, but kept this from his family as he did not want them to feel obliged to socialise with him (for further discussion of loneliness, see Koivunen, 2014, Paper 3).

Some older people in the study saw the installation of telecare as a way of reassuring their families and reducing the 'burden' on them; some felt telecare provided an alternative emergency response, or gave their families and friends 'peace of mind' between visits. Concealment and deception also featured in relation to telecare; for example, some participants distinguished between 'proper' falls, when they needed

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[12] Their identity-management strategies sometimes had unintended, and negative, consequences for other areas of their lives. For example, withdrawing from social contact to reduce social embarrassment might enable an older person to preserve their sense of self and dignity, but also led to social isolation and loneliness (see also Koivunen, 2014, Paper 3). 'Keeping things as they are' was an active choice for some participants, enabling them to retain particular features of their identities.

[13] This could have some negative effects, however. Mrs White (76, living alone, Oxfordshire) described feeling 'torn' between keeping their home as it was, in tribute to her late husband, and feeling upset by having reminders of her loss all around her.

to use their pendant alarm, and 'slips', 'trips' or 'stumbles' (see also Hamblin et al., 2013), when they did not. The latter were generally kept from family members, at least initially. For them, the key distinction between falls when telecare was used and those when this was not, to their minds, necessary was whether they could get up unaided. As one explained, recounting a fall in her bathroom:

> Mrs Cash: *I did get up on my own* [...] *I fell, but I am independent. If I can get up and do it, I want to do it* [...]
>
> Interviewer: *When you told your daughter about it, was she worried?*
>
> Mrs Cash: [She said] *'Why ever didn't you call me?'* [...] *Well, it was a Friday and it's her very long day [at work]. She doesn't usually finish till about six or seven and, well, I didn't want to bother her or my son for that. They both said, 'Why didn't you tell us? We'd have come.' I said, 'I know you would have done, but if I can manage, I will manage'.*
>
> <div align="right">Mrs Cash, 76, living alone, falls, Oxfordshire</div>

The telecare devices most widely available to respondents were pendant alarms, which allow the user to assess risk as they require the alert to be manually activated, a feature valued by most participants. Fall detectors, by contrast, have an automatic trigger, sometimes causing false alerts which some participants found distressing, as they felt these created an unnecessary burden for their nominated responders. Concerns over false alerts led some participants to remove telecare devices worn on their person, such as pendant alarms and fall detectors, particularly at night or when showering and (in a few cases) to cease using them altogether. The same was also true of bed sensors, especially when there had been several incidents of false alerts, as happened in some cases in the study. Family members, friends or neighbours affected by these false alerts were more tolerant of them, however, and were usually more troubled if they found the older person had fallen but not activated their alarm, or had not been wearing their device, which in some cases caused tensions between them. A further concern for some participants was the risk or likelihood of admission to hospital following a fall if they activated it, which for some acted as a deterrent to doing so (false alerts are also explored in Koivunen, 2014, Paper 3).

For some participants, the end of employment had created a sense of loss. Strategies to manage this included developing new hobbies, or putting work skills to new use. Mrs Allen (84, living alone, Oxfordshire) used her former work skills when she joined the committee at her new sheltered accommodation as the finance officer, providing her with a sense of self-worth and helping her to build new social connections.

Bodily changes which limited their activities or affected how others viewed or treated them represented a major challenge to research participants' identities as active and independent people (Fry, 2014, Paper 4). Some rationalised restrictions to activities caused by new or developing frailties as 'part of the ageing process' or lifecycle:

> *I'm just finding it very difficult to wind down and I want to do things that I did before* [...] *I'm having to accept being old* [laughing] *and not being able to do these things. I know I can't.*
>
> <div align="right">Mrs Robinson, 77, living alone, falls, Oxfordshire</div>

Others found it helpful to compare their own situation with that of peers; this encouraged some to do more and reassured others that their situation 'could be worse'. Within the sample, some older people were proud of the activities they could do unaided, particularly compared to other people of similar age who, they said, were now 'old'. This transformation of others into 'old' persons was shaped partly by how active they were and partly by their perceived outlook on life. These participants stressed the importance of retaining interests, and were keen to demonstrate their hobbies and activities, which included baking, quilt-making, crochet, knitting, sewing, woodwork and gardening; some took photographs of these as part of their contribution to the study (Box 5.1).

Box 5.1 Research participants' photographs of hobbies

Mrs Robinson, who was 77, lived alone in Oxfordshire. She had been passionate about sewing all her life. In her younger days, she had used her skills to supplement her income, but now she sews and does patch-work quilting for pleasure. She was keen to show examples of her work, including wedding and bridesmaid's dresses, quilts and upholstered furniture.

Mr Crosby was 79 and lived in Leeds with his wife who has dementia; he was her main carer. He started baking on the advice of a dietician when his wife started losing weight. Mr Crosby was an engineer and described himself as someone who likes to know how things work; for him, baking was a new and welcome challenge. He is now enthusiastic about baking, particularly bread, and uses the Internet to search for new recipes.

Mr Bush loved gardening, but over time he had needed to adapt his hobby. He was 81 and lived with his wife in Oxfordshire. When they moved into their current home, the smaller garden meant he had to shift his interest to smaller plants. When problems with his spine made it impossible to bend, he raised all the beds and shelves in his greenhouse. Mr Bush used his tablet to order new plants and to communicate with other growers; he also had several digital photo frames which proudly displayed images of his plants.

As capabilities changed, some adapted valued activities, often with considerable creativity, as a kind of 'identity management' strategy. Others, including some with very limited mobility, changed their expectations, taking pleasure in things they previously considered mundane, such as shopping trips or visits to garden centres.

Issues around independence were linked to feelings about being defined or seen as 'old'. Some combated these feelings by removing, re-evaluating, or 'reframing' 'old-age identifiers', such as walking sticks and frames, to reduce the stigma they associated with them.[14] In some instances this response extended to the telecare equipment provided, as already described. However, although many AKTIVE research participants felt the telecare equipment they wore on their person (pendant alarms, fall detectors and GPS systems) was unsightly, most considered them to be a 'good idea'; some participants had positive experiences of telecare which changed their perceptions; for some it was 'life saving'.[15] Others would have liked these devices to look more attractive, but could overlook the aspects they disliked if they helped them remain independent and active (the principal aim for most) and eased the concerns of their friends and families. After a period of adjustment, some re-evaluated their telecare as enhancing independence, rather than indicating dependence. One remarked:

> People say, 'Would you like some help now?' At first it was difficult to accept […] but once you realise that it starts to open up a different way of looking at things and giving you back a bit, more rather than taking it away […] That's thanks to the pendant as well. I mean, even going out today, I went into town, I didn't worry too much because I knew that if [my husband] had a bad turn he could just call them. Again, that gives you that little extra, and although you think it's taking your independence away, because you're asking for help, what it's actually doing is enabling you to do more, when you think about it.
>
> Mrs Swallow, 67, living with her husband, falls, Oxfordshire

An example of reframing the use of telecare as a way of enhancing independence and retaining a sense of self is explored in Box 5.2.

Changes to research participants' homes, including who was permitted access and the re-arrangement of physical space and furniture, caused concern among the sample, as outlined earlier in the paper. Differences in the degree of choice and involvement older people had been allowed in these changes seemed to affect who did, and who did not, feel these changes had damaged their identity.[16] Those who felt such changes had been imposed on them without discussion or consent felt particularly aggrieved; conversely, those who had been involved in the decisions more often saw the changes as sensible and necessary steps which allowed them to remain in their home. Some who felt they had been denied choice returned their homes to former layouts, reasserting their control over their living space.

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[14] The term 'framing' is used here in line with Goffman's (1974) approach; he argued that conceptual frames are the means to organise experience and structure perceptions of society. In this context, 'reframing' refers to the re-evaluation and redefining of changes (including telecare) to better fit with participants' identities.

[15] Some others in the study felt their telecare equipment had 'failed' in some way, as discussed in Hamblin (2014, Paper 6) and Buckle (2014, Paper 7), both forthcoming in this series (May 2014).

[16] A few consciously opted not to make such changes, sometimes because of their expense (for stair lifts and wet rooms, for example) or because of a strong preference for keeping their home in a familiar arrangement.

> **Box 5.2   Telecare as an identity management strategy: active and independent**
>
> Mr Lindsay lived with his wife in Leeds. Three years ago, following difficulty with some work tasks because of problems with 'seeing things' he was diagnosed with early-onset dementia and needed to retire early. He found this hard, as work had been an important part of his identity. He had always been very independent and had travelled a lot with his job. Following his diagnosis, Mr Lindsay began to go on long walks with the family dog. While this helped preserve his sense of independence, his wife became increasingly anxious about it, creating tensions between them.
>
> Following assessment for telecare, Mr Lindsay was allocated a GPS tracking device linked to a monitoring centre, which he could activate if he became lost and which enabled the monitoring centre to locate him for his wife if he did not return home. His wife liked the idea of this reassurance, and felt that if he wore the device she could be more relaxed about the length of his walks.
>
> During research visits, Mr Lindsay explained that he had initially been reluctant to use the device, as he felt capable of finding his own way home. Over time, however, he came to view it as enabling; it reduced his wife's anxieties and meant he could go on long walks without feeling he had to stick to a particular route or time. In discussion with the researcher, he presented the device as a sensible precaution against other possible occurrences (where the risk was not particular to his age or condition), such as falling over a tree root in the woods or being mugged.
>
> His account showed that he had 'reframed' how he viewed the telecare equipment, minimising its stigma as a device for someone who could become confused because of dementia, and presenting it instead as something he was willing to use to address risks relevant to any dog-walker. He subsequently used the device, taking pleasure in remaining independent when walking the dog (a new activity which he found helped fill the gap left when he had left work), giving valued reassurance to his wife, and reducing undesirable and unnecessary tensions between them.

Others reframed the changes as 'future-proofing' their homes, arguing they did not need the changes now, but might do 'one day'. Telecare was for some participants the 'least worst' option in terms of changes to their home; it was, comparatively, a small price to pay for the ability to return to or remain in their own home. Many participants, particularly those living alone following the loss of their spouse, or recovering from falls or injuries, came to view telecare as a sensible and rational option for anyone in a similar position. Box 5.3 outlines an example where a participant faced a choice between telecare or moving in with a family member.

The need for support from home care workers concerned many research participants, both those who were opposed to home care in principle and those who had experienced it first-hand. Some of the latter managed this change by reflecting on the assistance their care workers provided and focusing on the positive elements. Some rationalised accepting home care as a 'trade-off'; it enabled them to remain in their own homes and communities, and family members or friends to continue with their paid work, leisure activities or childcare. Others, finding certain care workers unsuitable, especially if young and male (a

particular concern for some women needing personal care), asked agencies not to send them again. Family carers had intervened in some of these situations to preserve their dignity and make them feel more comfortable about the arrangements. Some research participants whose concerns had not been resolved ended their contract with the care provider. Mrs Tyne, for example, (94, living alone, Oxfordshire) did not retain the services of care workers beyond the period of her re-ablement service, as she felt '*You lose all your dignity.* […] *I used to hate having to have men washing me and such like. I hated it'.*

Box 5.3   Telecare as an identity management strategy: home and place

Mrs Robinson was 77 and lived alone in a bungalow in Oxfordshire. She had been hearing impaired for more than 30 years and suffered from a condition which caused her to 'black out' without warning. During one of these episodes, she had fallen and damaged her spine, which had affected her subsequent mobility. Her daughters were concerned about these incidents and suggested she have telecare installed. When she expressed concern about the potential cost of this, her daughters proposed that she move in with one of them instead.

Reluctant to leave her home, Mrs Robinson then opted to have a pendant alarm and a fall detector installed. Although she felt 'pressured' into this decision, she understood her daughters' concerns about living alone, remarking during the first research visit:

'My daughters have forced me into all this, otherwise it wouldn't have. I wouldn't have done any of it. I wouldn't have asked for help or anything'.

Until the issue of the cost of these devices was clarified, Mrs Robinson was reluctant to wear either device (financial assessments at the time took 4-6 weeks), and she remained sceptical about the fall detector, describing it as 'cumbersome' and feeling concerned that she might set it off accidently, not realise this (due to her hearing impairment) or hear the monitoring centre staff's response, and be unable to cancel it or to respond.

Over time, however, she came to value the pendant alarm for the peace of mind it provided her and her daughters. It also gave her confidence to do more in her home and garden, and her mobility improved. She explained that the pendant alarm reminded her to 'go steady':

'I'm just more careful. I feel safer with this round my neck. It's just general things. I'm more careful with my step, what I do'.

Through her involvement in the study, Mrs Robinson's telecare package was upgraded to include a temperature extremes sensor and a bogus caller alarm. Both these additional devices made her feel more secure in her environment. By the end of the study, Mrs Robinson had become a keen advocate of telecare, and was encouraging neighbours to consider it as a support option.

To manage their identity in social interactions and their status as a local community member, some participants had withdrawn from their local communities, often fearing that their altered competence, and for some incontinence, would cause social embarrassment. Of particular concern were potential or actual social embarrassments caused by bodily changes (incontinence, difficulty in managing personal care, or others' perceptions of their frailty or memory problems). A few tackled these issues by changing their medication or consulting health professionals for advice. Research participants who felt changes to their body affected how they felt as a man or woman managed this issue by continuing to 'make an effort' with their appearance, such as by arranging mobile hairdressers. Some of those who felt less safe and secure because of their own frailty or changes in their neighbourhood or community managed these developments by accepting telecare equipment which could provide relevant support, such as the 'bogus caller' alarms which were installed in some homes during the study, and which some found particularly reassuring. During the study, a few participants decided to move home for their own safety or wellbeing; this was often a source of sadness, but after a period of adjustment, some spoke positively about the benefits of this, such as wardens, social activities, proximity to family members and more manageable spaces.

3   Discussion: telecare, identity and choice

This paper has highlighted some of the complexities which arise when telecare is installed at a time when older people's identities are being altered or threatened by changes in their everyday lives. The method chosen for the study (ELA) gave research participants opportunities to reflect on their lives and biographies, revealing how their past and present identities were bound up with roles they had enacted. Many were keen to speak about who they 'once were', how different (or not) they now felt, and what had changed in their lives.

Identities continually shift throughout the life course, but older people who are becoming physically or mentally frail can feel diminished by threats or damage to valued aspects of their identity and stigmatised by ageing, ill-health and new forms of dependency. As has been shown, research participants were often creative in their efforts to preserve their identities, and the installation of telecare helped some to preserve their identity as an active, independent or capable person. For others their telecare equipment was a source of stigma or embarrassment, however. This seemed to be the case if it was associated with other adaptations and aids perceived as markers of old age; if they felt it had been imposed upon them; if it was perceived to be unattractive; or if it was in some way troublesome.

Some research participants were unclear about who had suggested or decided that telecare would be useful, or how it had come to be installed. For some it was 'part and parcel' of a range of changes made following discharge from hospital or bereavement when they became the sole occupier of their home; times of confusion and great distress. Telecare was accepted by some as part of a 'deal' with relatives or professional advisers through which they were 'allowed' to return to or remain in their own homes. Very few participants had sought telecare actively and independently of their own volition; most thought it had been suggested by a family member or a professional in the health and social care system, and before it was introduced many had little idea what telecare was, could do, or how it worked. Months, and sometimes years, after it had been installed, some still had limited knowledge or understanding of the equipment, and while this was unsurprising for some with relatively advanced memory problems, in many cases there had been missed opportunities to support users to accept, understand and embrace the equipment (acceptance of telecare is also discussed in Fry, 2014, Paper 4).

Because of these factors, it is not possible to describe the introduction of telecare as an 'identity management strategy', although, as has been shown, some older people in the study had been very creative in responding to challenges to their identities and some recognised that telecare was helping them to hold on to highly valued aspects of their lives, such as living in the home they liked and wished to stay in, and retaining sufficient independence to feel in control of their everyday life.

Nevertheless, deciding to retain the telecare device(s) allocated and to use them to support valued identities was part of an active identify management strategy for some. Despite their concerns about telecare and some incidents of equipment not working as the user wanted or expected, telecare was positive for many as it provided the vital 'back-up' to feel confident or to be 'allowed' by others to continue living independently in the community. For many of the 60 older people in the study, some areas of their homes and gardens were now inaccessible as a result of injury, illness or disability. Defined as 'risky' or 'out

of bounds' areas by some research participants, and / or those who cared for or supported them, these 'high risk' areas included gardens, staircases and the upper floors of houses; telecare helped make these risks manageable and acceptable. It also played a role in making them feel safer and more secure in (and in some cases beyond) their homes, reassuring their families and friends; and it helped them retain highly valued aspects of identity, notably independence, the ability to remain in their own homes, and positive family relationships (see also Hamblin, 2014, Paper 6).

Its appearance and connotations, however, meant some telecare equipment also affected participants' identities in negative ways; many perceived it as unattractive and as a signifier that they had become old. Particularly if introduced alongside broader support packages, it often became associated with stigmatising items such as wheelchairs, walking frames, hoists and commodes, and the way some items of telecare equipment look and make older people feel thus represents both a barrier to use (particularly for items designed to be worn) and a threat to identity.

There was therefore a 'trade-off' between how telecare made people feel or look and its contribution to their identities as active, independent and embedded in places and communities which they valued. There is nothing inevitable about this compromise, however: telecare could be redesigned and repackaged as a set of desirable items which older people would enjoy having and using, rather than see as the 'least worst option' among alternatives which reduce their self-esteem and damage their sense of self.

Today, the daily lives of people of all ages are filled with technology which is not only *needed* but also *wanted*. Telecare equipment could be designed and introduced, with ongoing support for older people and those involved in their care, to realise its full potential as a contribution to richer later lives. Shifting its image from a source of stigma to one of pride would enhance older people's ability to 'be themselves' and retain their dignity as they age. The challenge for telecare manufacturers, designers and service providers is to create, introduce and provide ongoing support for telecare devices which older people not only tolerate, but see as desirable and essential supports for their wellbeing in later life.

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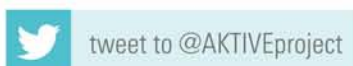
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